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Assessment of capacity to give informed consent for Medical Assistance in Dying (MAiD): A qualitative study of clinicians' experience.

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Key words: Medical Assistance in Dying; informed consent; capacity

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Introduction

In 2016, Canada's parliament passed *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, known as Bill C14. The law permits physicians and nurse practitioners to give a lethal substance to any patient suffering from a "grievous and irremediable medical condition" who voluntarily requests medical assistance in dying and satisfies the eligibility criteria (1). The Act requires that patients "give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care" and that clinicians "immediately before providing the medical assistance in dying […] ensure that the person gives express consent to receive medical assistance in dying". Quebec physicians are additionally subject to the provincial *Act respecting end-of-life care*, which likewise requires patients to provide "free" and "informed" consent (2). Both of the two independent clinical assessors required by law to evaluate an individual's MAiD eligibility are obliged to assess the patient's capacity. Additional clinicians may be asked to do a capacity assessment as well.

Having legal capacity means being able to understand the information relevant to making a decision about treatment and being able to appreciate the reasonably foreseeable consequences of making that decision (3). All forms of medical intervention performed by clinicians require informed consent (4). Informed consent is task, context, and time specific and requires voluntary choice in a patient who has been adequately informed and who has capacity to consent (4–7). The assessment of capacity can be affected by contextual factors including the experience and values of the assessor. For example, Ganzini et al. (8) found that assessors with previous bias against assisted dying are more likely to find patients incapable than those who accept assisted dying as a potential end-of-life choice.

Various tools have been validated for capacity assessments, such as the Aid to Capacity Assessment (ACE) (9) and MacCAT-T (10). None of these has been validated specifically for MAiD, but most accepted tools include the following elements:

1. Understanding information relevant to a condition and recommended treatment;
2. Appreciating the nature of their situation and the consequences of their choices;
3. Reasoning about the potential risks and benefits of their choices;
4. Expressing a choice.

The presumption of intact decisional capacity is a bioethical standard (5,11). Only where there is evidence the patient does not understand or appreciate the decision may the presumption of capacity be displaced (3). Patients with dementia can lose their ability to provide informed consent to medical treatment due to loss of cognitive functioning (12,13), but their capacity can fluctuate (14–17). In dementia, the domain of understanding has been shown to be most frequently deficient, as it relies most heavily on short-term memory (12,15). When mental illness impairs capacity, it most often affects the "appreciation" branch, which reflects insight (18). Patients may lack insight where their psychiatric illness is concerned, but still retain full insight where other medical illnesses are concerned. Patients who are incapable due to an acute exacerbation of a mental illness, such as a manic or psychotic episode, can regain capacity with treatment and therefore may require serial assessments. When assessing patients with communication barriers, it is not their communication skills but their decision-making capacity that must be assessed. In order to do so effectively, assessors must facilitate and maximize a patient's communication abilities (19). This may include augmentative and alternative communication systems, ranging from low-tech (e.g a quiet room, a translator) to high tech (e.g. electronic speech devices) to facilitate communication.

In this paper we focus on the practical aspects of assessing capacity to consent to MAiD by exploring the experience of MAiD clinicians across Canada.

Methods

We recruited participants using both the English and French MAiD provider list-serves. Two of the investigators did the interviews (MK in English, STH in French) using phone, video or email. The interview guide was developed with the help of the Canadian Association of MAiD Assessors and Providers Working Group on Assessment for Capacity to give Informed Consent for Medical Assistance in Dying (MAiD). We asked participants about their experience in assessing capacity for MAiD, any challenges or problems they faced and what resources they used (Appendix 1).

The interviews were audio-recorded and transcribed verbatim. STH translated the French transcriptions and the whole team did the analysis in English. We read the transcripts as they were posted and met regularly to discuss emerging themes and to decide which areas should be explored more fully in an iterative manner. For example, when we realized that only some participants described the challenges of assessing patients with mental illness diagnoses, we contacted previous interviewees and asked more questions about this issue. We used detailed coding to discover themes and subthemes from the interview data (20). We then met to discuss themes, sub-themes, and coding until we arrived at consensus. This study was approved by the University of British Columbia Research Ethics Board (H15-03198) and the Ontario Tech University Research Ethics Board (15221).

Findings

We interviewed 20 MAiD assessors/providers between August 2019 and February 2020. Their ages ranged from 36 to 82 (mean age = 56), and they lived in five provinces (British Columbia, Manitoba, Ontario, Quebec and Saskatchewan); eight were from Quebec and twelve were from the rest of Canada (ROC). Fourteen worked in an urban setting, four worked in a rural setting, and two worked in a mix of both urban and rural settings. Their clinical backgrounds included work in palliative care (9), geriatrics (4), emergency medicine (2), intensive care (2), reproductive health (2), psychiatry (3), and general medicine (4). They spoke of diverse experiences working in hospitals, clinics, communities and homes. The participants had assessed between 8 and 500 patients for MAiD (mean assessments = 120.5), and collectively they had completed 2410 assessments at the time of their interviews.

The most important theme was that they usually gathered the information they needed through a conversation with the patient about how that individual had come to choose MAiD. They were comfortable assessing capacity and rarely referred for formal assessments.

> “So you know, it’s more my clinical experience, to chat, to discuss with the patient, and how I cross-check that with the patient’s file, and I say: ‘Well look, evidently he’s coherent, he tells his story exactly, and he explained to me the road that allows me to determine why this patient made a MAiD request, he is aware of his diagnosis, he is aware that his diagnosis is terminal, and he wants to put an end to his life or to his struggle, because for him, it doesn’t make any sense’” (#7, MD, PQ).

> “I think my capacity assessment really stems from having a conversation with the patient and asking them to talk to me about their life and about their experiences and it’s through the answering and the understanding of those questions on their part that helps me to determine whether they have capacity to make this decision or not” (#9, NP, ROC).

> “It’s maybe happened two or three times that I asked an opinion from the psychiatrist, because it was a request that seemed a little peculiar. And I wanted to be sure I was backed in my decision with respect to capacity” (#4, MD, PQ).

The Quebec providers, whose assessments are subject to review from Quebec’s Commission on End-of-life Care, were more likely to say they used a tool, specifically the Nova Scotia criteria, to assess capacity [51,53].

> “it’s always the Nova Scotia criteria, specifically, it’s if the patient understands his illness, understands his prognosis, understands the options, understands what MAiD means, the advantages and disadvantages, and is able to reason, to reflect on that” (#4, MD, PQ).

When we asked about challenges and problems they had faced, participants described patients who were non-verbal or were so ill that they tired too quickly to have lengthy conversations, ones with fluctuating capacity and ones with early dementia. They talked about the ways they tried to foster the conditions in which the patient could demonstrate capacity.

> “And I’ve learned more about that, about facilitating capacity, which means that you choose the right time of day and you make sure that the light is okay and it’s quiet and that they’ve got their hearing aids and their glasses on” (#10, MD, ROC).

> “…using simple language, being very repetitive. Simple language, slow language, so one item at a time, as opposed to a multi-layered sentence, or multi-layered question or something like that. Lots of repetition, lots of recall tests and checking in” (#17, MD,

> ROC).
>
> “And so, you might…want to go back and do repeat assessments, especially if they don’t want the death right away, to make sure that they still have capacity” (#18, MD, ROC).
>
> “I really learnt a lot due to the help of the speech language pathologists. We’ve actually put together kind of a toolkit with a lot of pictures and schematics and stuff for patients with aphasia” (#17, MD, ROC).

They also used assistance and corroborating evidence from family and caregivers.

> “I love having more ears involved, so I involve families as much as possible and that helps a lot too in helping mom or dad stay focused and determining whether they can get back on track and understand this. And I even use – if my language isn’t right, then can their children come up with a different question? Can they reframe it to help mom or dad understand it better?” (#11, MD, ROC).

In challenging cases the providers often look for consistency, not only of the request for MAiD but also of their long-held values. This information sometimes came from family or caregivers.

> “And in this particular patient’s case, MAiD was something he had always been enthusiastic about, so if the request is consistent with their values, even if their assessment is somewhat borderline, I often do feel comfortable saying that it’s safe to proceed. That’s one of my litmus tests” (#16, MD, ROC).

When they discussed using capacity assessment tools, they used them less for the assessment itself than for meticulous documentation. We heard this more from our Quebec participants.

> “I will go through the rigmarole (of using a capacity tool), because I know somebody may ask for my file, or somebody might contest, or a family member might contest” (#3, MD, PQ).

The most common situation in which they assessed someone as not eligible due to lack of capacity was in terminal delirium. They talked about expediting provision in cases they assessed as at risk of losing capacity.

> “I think the patients that I had to deem ineligible because of capacity were clearly far along in their illness trajectory and were very close to their natural death” (#9, NP, ROC).
>
> “And so he went through a very rapid decline and so we expedited, but that day, he had already, by one o’clock in the afternoon, by the time I got the second assessment done, he actually couldn’t say yes or no anymore” (#13, MD, ROC).

> “It’s that a lot of patients refuse to receive palliative care medication by fear of losing their capacity to consent in the process” (#6, MD, PQ).

> “So, I won’t say ‘it’s now or never’, but I’ll kind of just say, ‘We’re not going be able to wait the 10 days, so we’re going try to get the two assessments in today and tomorrow and pick a date as soon as we know that both physicians feel you qualify” (#19, MD, ROC).

Some participants referred to their intuition or gut-feeling making them want to take further steps to verify the patient’s capacity.

> “You know, sometimes it really is two patients who are very similar, but with one of them you feel confident, and the other you don’t, and it’s hard to put your finger on why that is” (#16, MD, ROC).

Except for the psychiatrists, most participants had no experience with “purely psychiatric” patients. With patients who had concurrent conditions, they usually used the same approach as with their other patients.

> “As mental health issues such as depression and anxiety are common in the chronic disease/cancer populations, I ensure capacity in a similar way with all patients– give patient info that is relevant to making informed decision, assess patient ability to understand the information, and also their ability to appreciate the situation and consequences” (#15, NP, ROC, by email).

> “I do not regard [a diagnosis of mental illness] as an exclusion criteria for MAiD, but I carefully assess whether I feel like their thought process and content are clear and goal-directed, or if they are hopeless beyond the rational assessment of their circumstances. If I feel they are unable to rationally assess their circumstances, I would ask for a psychiatry opinion. This has not happened to me yet, as I find most patients requesting MAiD to have been quite rational in their thinking, despite some demoralization and their request for hastened death” (#12, MD, ROC, by email)

Interpretation

The 20 participants in this study were from all across Canada, represented different medical specialties and collectively had a great deal of experience doing MAiD assessments. They felt confident with most assessments and relied on conversations with their patients about their choice for MAiD to get most of the information they needed. They were experienced clinicians who had assessed patients for other medical procedures, which may account for this finding.

When they discussed challenging cases, they recognized that capacity fluctuates, and were sensitive to the conditions of assessment such as time of day and environmental factors. They used aids that facilitate communication (e.g. hearing aids/ glasses). These aids may have an impact on capacity itself, since confusion and distraction arising from communication barriers can impede a patient's ability to understand and appreciate decisions (19,22-25).

Most of the cases in which they found someone ineligible for MAiD due to lack of capacity were close to death and had varying levels of terminal delirium. This was tied to their discussions about waiving the 10-day reflection period to prevent loss of capacity before the planned date.

Our Quebec participants were more likely to use and document the "Nova Scotia" criteria than participants from the rest of Canada, but all participants talked about using the same basic elements of understanding, appreciating, reasoning and expressing a choice (9,10,21).

Our study was limited to only 20 assessors but did capture the experience of clinicians from different geographic areas and specialities. Further studies could examine this issue with more clinicians so that we could understand how their background affected their experience and approach. It is also important to investigate how the changes proposed in Bill C7 will affect capacity assessment for MAiD and how best to help trainees learn to do these assessments.

Conclusion

The participants in this study were comfortable doing MAiD assessments and used their clinical judgment and experience to assess capacity in similar ways to how they did in their other clinical practices.

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Appendix 1

Interview Guide

Physician or NP Interview:

- What is your experience with assessing and providing MAiD? (numbers)
- How long have you been doing this?
- How many patients have you assessed?
- How many did you deem ineligible due to capacity? How many did you refer for forma; capacity assessments?
- Now I would like to ask you about how you assess for capacity. Has this changed over the time you have been doing assessments?
- Can you describe to me a situation where you found it especially difficult to assess a patient’s capacity to choose MAID?
- Do you find that assessing capacity for MAiD is different than other situations such as stopping treatment?
- What have you found most helpful in assessing and documenting capacity for MAiD in —capacity assessment tools, previous experience, CMPA, the CAMAP guideline, College guidelines, talking with other MAID providers?
- Do you think the current legal eligibility criteria for capacity at both request and provision times should be changed?
- Have you been involved with patients where there was a disagreement between the physician/NP assessors about capacity?
- Have you had any adverse ramifications (ie: legal, licencing, conflicts with the family, etc) due to the uncertainty of the patient’s capacity?
- How did you receive training to become a MAID provider (ie: self-directed learning vs exposure during residency)? Were you aware of the specific issues around assessing capacity for MAiD?

Demographics

Age, gender, MD or NP, Canadian graduate, practice type (primary care vs specialists, full time vs part time), rural or urban